Development of the Cancer Survivorship Care Plan: What’s Next? Life After Cancer Treatment

Jody M. Jackson, RN, BSN, Kathy Scheid, BS, RD, and Sharon J. Rolnick, PhD, MPH

Long-term information needs are increasingly important as more people are diagnosed with cancer and living well beyond initial diagnosis and treatment. Consequently, cancer is joining the ranks of chronic conditions (e.g., asthma, diabetes) for which ongoing, long-term surveillance and management should be the model of care. However, the post-treatment period is fraught with uncertainty for patients and care providers. The “who, what, and when” of follow-up care, in particular, can be complex and confusing. Therefore, survivorship care plans (SCPs) are recommended. The Minnesota Cancer Alliance, a coalition working to improve quality of life for cancer survivors, developed a patient-focused SCP. This user-friendly SCP could be considered for use in patient care—particularly by nurses, who are well suited and positioned to implement SCPs.

Post-treatment issues have become increasingly important as more people are living well past their initial cancer diagnosis because of advances in early detection and therapeutic technologies. According to the National Cancer Institute (NCI), about 4% of the U.S. population (14 million individuals) are cancer survivors (Howlader et al., 2011). Sixty-seven percent of adults diagnosed with cancer will be alive five years postdiagnosis, and more than 75% of childhood cancer survivors will be alive after 10 years. For many patients, that survivorship period extends beyond the traditional five-year benchmark; according to the NCI, 15% of all cancer survivors were diagnosed 20 or more years ago (Howlader et al., 2011). For many, cancer is becoming another aspect of life rather than a threat to it. Living with cancer often means living with a complex chronic condition (Phillips & Currow, 2010). In a survey of survivors conducted by Miedema, MacDonald, and Tateuchi (2003), 36% of respondents were unsure which physician was in charge of their cancer care. In addition, in a survey of primary care providers (PCPs) conducted by Nissen et al. (2007), more than 84% reported uncertainty regarding the type, frequency, and duration of surveillance tests for their patients with histories of breast or colorectal cancer. Cheung, Neville, Cameron, Cook, and Earle (2009) surveyed patients and providers and found that (a) patients believe that their oncologists should be more involved in follow-up care than oncologists think they should be; (b) PCPs believe they should be more involved in follow-up care than their patients believe; and (c) oncologists and PCPs disagree about who is responsible for surveillance, other cancer screenings, and preventive health care for patients with cancer. With the increasing number of survivors and length of survival, as well as the discrepancies among key players regarding follow-up care, providing patients with information about their long-term survival has become more important.

Cancer survivorship care plans (SCPs) have been proposed by leaders in the cancer care community to help address uncertainty during the survivorship period. An SCP has two components, a treatment summary and a care plan that act as a record and a guide, respectively. The care plan summarizes details of diagnosis and treatment, as well as provides information...